

# Autism and Advocacy



A briefing paper from the **Autism and Advocacy Network** calling for action to improve access to advocacy for autistic people and their families across Scotland.

Access to advocacy for autistic people is currently a postcode lottery of commissioned and grant-funded services, often part of statutory advocacy provision, such as services provided to individuals subject to the Mental Health (Care & Treatment)(Scotland) Act 2003 , or short-term grant funding from charitable foundations. This paper seeks to highlight the need to guarantee nationwide advocacy provision for all autistic people.

## Introduction

The Autism and Advocacy network is facilitated by Autism Network Scotland and is open to any organisations or individuals with an interest in improving advocacy for autistic people and families.

The Network currently includes representatives from: AISee, The Advocacy Project, Central Advocacy Partners, Signpost, Partners in Advocacy, Autism Coordination Resource Hub - South Lanarkshire Council, Renfrewshire Autism Neurodiversity Project, Hope for Autism, Scottish Independent Advocacy Alliance, as well as a number of individual professionals, parents and autistic adults.

There is a national strategic context to meeting the challenges that autistic people and their families face to access advocacy. 'The Promise' report, The Cross Party Groups' Accountability Gap report and the ASL Action Plan all recognise the need for autism and neurodiversity awareness within advocacy services, as well as a scaling up of a range of such advocacy services to incorporate community assets. Indeed the Scottish Government explicitly stated their intent on exploring the Community Based Asset approach in their 'Towards Transformation' report for autism and learning difficulties.

## Background

Families, individuals and communities/groups of people may need a range of different types of advocacy and it is vital that the needs of those who need advocacy get this in the most appropriate form . The concerns about autistic people and families accessing appropriate advocacy services was recognised by the Scottish Government as part of the refresh of the Autism Strategy for Scotland, Outcomes and Priorities 2018-2021.

‘A large number of participants raised the importance of advocacy and advocacy services for autistic people, which were described as being **‘worth their weight in gold’** and **‘essential’** for people on the spectrum...**to enable [them] to have a greater understanding of their situation and to give their views’**.

This led to Autism Network Scotland producing a summary report to Scottish Government in 2018, the two main outcomes of which were:

- The development and successful piloting of a training programme initially targeting families and taking a positive collaborative partnership approach.
- The establishment of an Autism and Advocacy Round Table group (now the Autism and Advocacy network) which discussed the need for policy change as well as agreeing a clear vision statement: **‘Scotland will have access to a range of Independent and Autism Informed Advocacy delivered at the right time, in the right way appropriate to need and delivered by the right people’**.

This range of advocacy support includes the full range of formats in which advocacy can be delivered including independent, self and peer advocacy. This range is required to respond appropriately to the unique way in which autism impacts on individuals, families and their consequential need for support and understanding. It includes low threshold community based advocacy to ensure families can get the support they need at the right time.

This paper does not seek to argue for or provide evidence of the importance to autistic people and their families to access advocacy. That point is now well established and reported on in many national reports and reflected in Scotland’s ambitions as a nation. Recent work of members of the Autism and Advocacy Network has found that there remains significant gaps for families / carers in awareness of advocacy and what it can offer. (Additional background on the key principles of advocacy and relevant academic research which make a clear argument for advocacy for autistic people and their families).

#### *The need (why it’s still not working)*

The Advocacy Round Table group did not expect that the vision statement alone would make the changes required, but that it does provide a clarity of direction and intent. We now need to address the challenges that are preventing this vision being achieved.

The Scottish Government’s responsibility for advocacy sits across several departmental portfolios. Whilst this is understandable given that access to good quality advocacy is needed across society, the disadvantage is that synergies of activity are not capitalised upon and there is a lack of coordination, cohesion and clarity.

In the absence of a national overview of advocacy services, funding is piecemeal and inevitably people fall between the gaps in advocacy provision.

Existing advocacy services work diligently, creatively and are achieving great outcomes for people but there is a danger that this is then perceived that current advocacy services are adequate. This is not the case, and particularly so for autistic people and their families. Often advocacy services are commissioned to address statutory entitlement, for example the Mental Health (Care & Treatment)(Scotland) Act 2003 (as amended) and the Children's Hearings (Scotland) Act; autistic people have to 'fit the criteria' to access independent advocacy support, and where they do not, they have no access to this important service and their rights are at risk. Some advocacy providers have sought funding from charitable foundations as they recognise the gap in provision for this vulnerable group over a range of issues, such as additional support for learning, transitions, accessing eligible benefits and services, health, further and higher education, and employment. Navigating these systems and processes can be daunting for an autistic individual, and a lack of knowledge of their rights can lead to rights' breaches and discrimination on account of their condition.

Advocacy for autistic people and their families, in whatever form of advocacy that takes, is often not a 'single issue'. This can restrict access to some advocacy services as well as requiring a longer term involvement which may not be available. Independent advocacy services are increasingly unable to meet the demand for local advocacy.

Advocacy support is not universally available and there are examples where autistic people are being turned away from advocacy services because their case is 'too complex', 'out with the eligibility criteria', and sadly 'you're not autistic enough'.

### *How to change this*

Recently the need for advocacy (including independent advocacy) has been highlighted in a range of national consultations and reviews. The Feeley review along with the Barron Review and John Scott QC review all make recommendations on the need for Independent Advocacy. We need to change the thinking about funding for advocacy services from it negatively being a cost to positively being a societal investment. It is clear that good advocacy support delivered at the right time can have significant long term savings, prevent greater needs emerging and enable successful outcomes, delivering a broad social return on investment.

1. A national initiative is needed to connect the various advocacy funding streams together and use these more creatively and break down the barriers that exclude people from advocacy services. Funding for advocacy needs to be protected and

given priority rather than it being funded as a side issue of other priorities. It also needs to allow for long term advocacy support rather than 'short fix' approaches for those who need this.

2. To ensure that everyone is able to access advocacy, a cohesive and integrated mechanism is needed to implement a process where there is an advocacy safety net to ensure that all individuals can access advocacy support when needed. This includes individuals or families with complex advocacy support needs. The nature of this 'safety net' needs further discussion and innovation with the bottom line of ensuring everyone who needs advocacy has a guarantee of equality of access and provision.
3. To ensure that the range of advocacy is provided, a greater commitment is needed and this includes more initiatives to support the development of self and peer advocacy.

### Next steps

The Autism and Advocacy Network want to engage with our elected representatives and others at a senior level whereupon we can work together to improve access to advocacy for autistic people and their families and thereby their outcomes.

**We therefore request a meeting with relevant representatives, cross departmental, to move forward with this agenda.**

### CONTRIBUTORS (Members of the Autism and Advocacy Network)

- Autism Network Scotland
- Central Advocacy Partners
- Hope for Autism
- Partners in Advocacy
- Scottish Independent Advocacy Alliance
- Signpost
- Autism Resource Coordination Hub : South Lanarkshire Council
- The Advocacy Project
- Individual Professionals
- Individual Parent/Carers
- Autistic Adults
- AISEE/International Advocacy Practitioners Association
- Renfrewshire Autism and Neurodiversity Project/Renfrewshire Carers Centre

## APPENDIX

### 1. Key principles

There is a real recognition at a local and national level for the need for autism-informed advocacy within autistic people's organisations, as well as by individual professionals and providers within the advocacy sector.

(This includes advocacy being highlighted in a number of recent reports and events: Listening to Community event Perth 2015, Positive Partnership events 2016 -2019, the Autism and Advocacy Exploratory Report 2018 , Autism and Advocacy Collaborative Day 2019, Autism and Advocacy Round Table 2019 -2020 and now the Autism and Advocacy Network).

From this appreciation and knowledge, we understand and recognise the importance for autism and other neurodevelopmental conditions that the principles are developed by frontline advocacy (professional, third sector and peer) practitioners and clients.

These Neurodevelopment Advocacy Principles define and promote key advocacy principles. Please note that independent advocacy providers follow the Principles, Standards and Code of Best Practice in Independent Advocacy, published by the Scottish Independent Advocacy Alliance, 2019. These align with the Neurodevelopment Advocacy Principles.

#### **Key advocacy principles (Based on work of International Advocacy Practitioners Association)**

Effective advocacy is a partnership and it must therefore be mutually (practitioner and client) acknowledged that appreciation, respect and understanding are core to delivery for beneficial outcomes.

##### **1. Clarity of purpose**

Advocacy providers must ensure their knowledge, organisationally and individually, is condition based and at sufficient level to ensure effective communication, understanding and how the condition impacts an individual in their dealing with associated service provision across criminal justice, education, employment, housing, health, social care and social security.

Advocacy providers' aims, objectives and planned activities are within the objects set out in its governing document and providers should be able to demonstrate how these meet the principles contained in this document.

Advocacy providers should ensure that the people they advocate with or on behalf of, health and social care services and funding agencies have information on the scope and limitations of the advocacy provider's role.

Advocacy providers, must recognise that for condition specific advocacy, may not be 'single' issue advocacy and must adapt accordingly.

## **2. Independence**

Advocacy providers must be operationally, politically and structurally, independent from statutory organisations, free from conflict of interest both in design and delivery of advocacy services, and seek actively to reduce conflicting interests. In particular where the organisation provides additional services such as housing provision, social care and they must at all times declare commercial interest especially if they are contracted by a statutory authority. It is appreciated that funding mechanisms can provide unintentional conflicts of both interests and practice.

## **3. Individualised Person Centred Approach**

Advocacy providers will ensure that the wishes and interests of advocacy partners (those in receipt of an advocacy service) are front and foremost in service provision. All advocacy practitioners should be non-judgmental and respectful of people's needs, views, culture and experiences.

Person-Centred Planning is a process of continual listening and learning, focussing on what is important to the individual now and in the future, and acting upon this in alliance with their family and friends. The input from Independent advocacy , representing the advocacy partner alone, is a vital component of this process.

## **4. Empowerment**

Advocacy providers will support 11 individualised, collective, peer, self-advocacy, and empowerment through its work, including with some conditions the enablement of supported decision making. Advocacy providers will accept and respect the determination of the level of involvement and style of advocacy support that an advocacy partner or group of autistic people want where they are able and wish to.

Where advocacy partners lack the ability or capacity to influence the service, the advocacy provider should have a process to enable those with an interest in the welfare of the person to influence this, for example a parent carer or legal guardian.

Providers will ensure that people who want to, can influence and be involved in the wider activities of the organisation, up to and including at Board level.

## **5. Accessibility**

Advocacy will be provided free of charge to all eligible people, and will aim to ensure that all policies, procedures and communications will promote access for all autistic people. Where an autistic individual lacks the capacity to instruct an advocate, a non-instructed advocacy approach can be adopted, in line with guidance produced by the Scottish Independent Advocacy Alliance (SIAA), in order to safeguard rights and question decision makers on behalf of such autistic individuals. Non-instructed advocacy safeguards the rights of individuals by asking questions of decision makers were the individuals able to do so themselves. This model of advocacy involves conducting observations of the individual in a range of settings, speaking to family members and professionals involved in their life to build a picture of their life, their preferences and what is important to them, and then conveying these in order that decisions are made taking these into account.

## **6. Accountability**

Advocacy providers will have systems in place for the effective monitoring and evaluation of its work, including identification of outcomes for advocacy partners. All those who access the service will have a named advocate and a means of contacting them.

## **7. Equal Opportunity**

Advocacy providers will have a written equal opportunities policy that recognises the need to be proactive in tackling all forms of inequality, discrimination, service and social exclusion. The advocacy provider will have systems in place for the fair and equitable allocation of advocates' time.

## **8. Supporting Advocates**

Advocacy providers will ensure advocates are suitably prepared, trained and supported in their role and provided with opportunities to develop their knowledge, skills and experience, in particular legislation, policy and condition specific communication techniques and knowledge.

## **9. Confidentiality**

Advocacy providers will have a written policy on confidentiality that is in line with current Data Protection legislation (GDPR) relating to the range of their services. It should outline how information about a client accessing the service may be shared, stored as well as the circumstances where confidentiality might be breached, and for how long data will be stored. Advocacy providers must also inform what unidentifiable data may be stored for research and medium to long term reporting purposes. Advocates must also be aware of situations that would require raising a child or adult- protection concern.

## 10. Complaints

Advocacy providers will have a written policy describing how individuals, including relevant stakeholders, can make complaints or give feedback about the service.

Advocacy providers will enable people who use its services to access external independent support to make or pursue a complaint, adding value to the advocacy organisation via reflective learning.

## 11. Safeguarding

Clear policies and procedures will be in place to ensure safeguarding issues are identified and acted upon. Advocates will be supported to understand the different forms of abuse and neglect, issues relating to confidentiality and what to do if a client may be at risk.

## 12. Code of Practice

This will vary from organisation to organisation depending on the provision of services. The Code provides a clear description of what is and is not expected of a practitioner in their day-to-day work with clients.

An effective Code of Practice can for example include

- Offer guidance to advocates in their role
- Inform advocacy partners of what they can realistically expect from their advocate/advocacy service
- Educate health, social care, third and private sector services, commissioners and others about the scope and limitations of the advocate's role
- Help to develop a better understanding of the training, supervision and support needs of advocates
- Raise awareness of the need for and benefits of independent advocacy for vulnerable people

*(This summary was compiled from, but not limited to, the activities of the previous events listed in the opening paragraph of this appendix)*

## 2. Advocacy: Research and Context

The following research findings highlight the need for advocacy services for autistic people:

***The Microsegmentation of the Autism spectrum: Economic and Research Implications for Scotland (2018) MacKay, Boyle, Connolly, Knapp, Lemmi, Rehill***



There are approximately 44,133 autistic people in Scotland, a prevalence rate of 1.035% (103.5 per 10,000) the cost of autism in Scotland is estimated to cost £2.2 billion per year

This paper evidenced the need for Independent Advocacy; autistic people and their families in Scotland are struggling to find suitable advocacy services, specific to the needs of autistic people.

'I have been trying for over a year to find an autism-specific advocacy service for my son because of decisions made by the Court, which he was given no say in. There does not seem to be any suitable

advocacy service in Scotland.' Micro-segmentation of Autism in Scotland Report (McKay Et al, 2018)

### ***The Scottish Strategy for Autism Consultation Engagement Analysis (2018)***

'Autistic people said they need to be listened to and included in the development of policies and services that affect them. Advocacy services for autistic people, 'worth their weight in gold' and 'essential' for people on the spectrum...to enable [them] to have a greater understanding of their situation and to give their views'

### ***Lee-Foster (2003) Autism: the demand for advocacy. National Autistic Society***

Research found that autistic people were often unable to access tailored advocacy services that met their needs. Lee-Foster (2003) revealed that the majority of advocacy organisations failed to support and prioritise autistic people and their needs, highlighting the lack of resources and capacity. The research asked Independent Advocacy organisations what challenges they found when advocating for autistic people, responses included; lack of understanding, communication difficulties and problems in building advocacy relationships.

### ***'Count Us In' National Autistic Society: It Pays to Listen report (MacBean and Synnot, 2013)***

National Autistic Society consulted with autistic people and their families in Scotland and found that only 16% had accessed advocacy. Autistic people themselves stated that they wanted information as to how and where to access Independent Advocacy services as they viewed the service as a way to help gain control and choice in their lives.

### **Other useful references:**

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\*MacBean, R. and Macdonald, S. (2016) 'Through the glass wall, in Wright, S.D. (ed.) *Autism spectrum disorder in mid and later life*. London: Jessica Kingsley Publishers.

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\*McClintock, K., Hall, S. and Oliver, C. (2003), "Risk markers associated with challenging behaviours in people with intellectual disabilities: a meta-analytic study", *Journal of Intellectual Disability Research*.

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Power, A., Bartlett, R. and Hall, E. (2016) 'Peer advocacy in a personalized landscape'.

\*Richardson, L., Beadle-Brown, J., Bradshaw, J., Guest, C., Malovic, A. and Himmerich, J. (2016), "'I felt that I deserved it' – experiences and implications of disability hate crime", *Tizard Learning Disability Review*.

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Venter, A., Lord, C. and Schopler, E. (1992), "A follow-up study of high-functioning autistic children", *Journal of Child Psychology and Psychiatry*

[Scottish Independent Advocacy Alliance https://www.siaa.org.uk/](https://www.siaa.org.uk/)

Scottish Strategy for Autism Outcomes and Priorities 2018 -2021 (March 2018) <https://www.gov.scot/Resource/0053/00533392.pdf>

Scottish Strategy for Autism, Engagement Analysis (March 2018) <https://www.gov.scot/Resource/0053/00533386.pdf>

The European Convention on Human Rights [https://www.echr.coe.int/Documents/Convention\\_ENG.pdf](https://www.echr.coe.int/Documents/Convention_ENG.pdf)

The Human Rights Act 1998 <https://www.legislation.gov.uk/ukpga/1998/42/contents>

The Scotland Act 1998 <https://www.legislation.gov.uk/ukpga/1998/46/contents>

The Scottish Commission on Human Rights Act 2006 [http://www.legislation.gov.uk/asp/2006/16/pdfs/asp\\_20060016\\_en.pdf](http://www.legislation.gov.uk/asp/2006/16/pdfs/asp_20060016_en.pdf)